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Vasculitis UK - Important initiatives

The Chairman has been very active during the past two months representing Vasculitis UK on two important initiatives which will, hopefully, bring the vasculitic diseases to a wider medical audience, and improve the lives of vasculitis patients.

Consultation on the UK Plan for Rare Diseases



This is a rather exciting time for rare diseases in general and for vasculitis in particular. Having been regarded for years as "Cinderella" diseases the spotlight is currently shining on them.

In February this year, the UK government produced a consultation document "Consultation on the UK Plan for Rare Diseases". This outlined the problems involved (including financial considerations) and some of the many ways of addressing them. Responses to the document were invited before 25th May.

Vasculitis UK submitted a response, as did other organisations such as Rare Diseases UK (who produced an excellent report) and the National Alliance for People with Rare Diseases. Vasculitis UK is a member of RDUK.

Improving NHS services for rare auto-immune disease

In April there was a meeting of the newly formed UK Vasculitis Rare Disease Working Group attended by most of the senior doctors working in vasculitis. Vasculitis UK was represented. This group also submitted a response to the consultation.



On 21st May another group met at the HQ of the Royal College of Physicians in London. This was a meeting between the members of the Independent Expert Clinical Group on Rare Auto Immune Diseases (led by David Jayne) and representatives from MHP (the consultants who advise the government on health policy), NICE (National Institute for Health and Clinical Excellence), the National Specialised Commissioning Team and representatives from Vasculitis UK, Lupus UK and the Myaesthesia Gravis Association.

This meeting saw the launch of the Independent Expert Group's report and recommendations "Improving NHS Services for Rare Auto-immune Diseases" - which is an excellent, comprehensive and readable document.

One of the consistent themes that came through in all of these meetings and reports was the need for central registries (or databases) of patients suffering from rare diseases. Because these diseases are rare it is essential that all the information about these patients should be brought together for sharing clinical experience and for purposes of research.



Camellias in the Isabella Gardens, Richmond Park. Photo by Vasculitis UK Member Ant Falla

What did you do for Vasculitis Awareness Month?



Rita Allen and friends - Essex tea party



Kelly Jefferies - Auction



Pat Fearnside and helpers - Coffee morning

The Rare Disease UK document "Improving Lives, Optimising Resources" is available at [Rare Disease UK](#) The Department of Health consultation document on the "UK Plan for Rare Diseases" can be found at their [website](#)

If you want to see the Vasculitis UK response to the consultation or the very interesting Independent Expert Clinical Group report, or if you cannot find the other documents online, then please contact [John Mills](#)

Diary Dates - *Something for everyone*

Please let the organisers know if you are going to attend. Also please be considerate and let them know if you are then unable to attend especially where refreshments are being ordered and paid for.



♦♦Comedy Charity Night, Roosters Bar, Warrington, Lancashire♦♦ In memory of David Booth. Friday 8th June with "Angel Delight". For details ring Kim 07517 626265

West Country VSG - BBQ Saturday 16th June in Teignmouth. Please contact Charlotte Stoner on 01626 872420 or [e-mail Charlotte](#)

Lincolnshire VSG - BBQ lunch, Sunday 17th June in Digby. All welcome, 12 noon start. Please contact Pam Todd on 01526 268106 or [e-mail Pam](#)

Surrey VSG The next Surrey meeting will be held at the home of Maggie & Paul Bingham on Sunday 24th June. Please contact Paul 01737 813389 or [e-mail Paul](#)

London (Dartford area) VSG The re-scheduled date is Saturday 23rd June at the Hurst Community Centre, Bexley. Please contact Jaqui Moran 07792 412768 or [e-mail Jacqui](#)

South Wales VSG The first meeting of this group will be held on Sunday 24th June at the Village Hotel, Cardiff. For full details please contact Jackie Thomas 029-2089-2403 or [e-mail Jackie](#)

Liverpool VSG (New) The first meeting will be held on Thursday 12th July at 3.30 - Royal Liverpool Hospital, Ward 11C. Please contact Keith Quinn 07923 015481 or [e-mail Keith](#)

Oxfordshire VSG Lunch at The Duke of Marlborough Hotel near Woodstock. Sunday 15th July. Please contact Sue Ashdown 01295 816841 or [e-mail Sue](#)

Lancashire VSG The provisional date for the next meeting is Sunday 16th September. Full details from Jann Landles 07795 547217 or [e-mail Jann](#)

West Midlands (VSGWM) The next meeting will be at the Hilton Hotel, Sunday 14th October. Details from [David Sambrook](#)

♦♦Charity Ball, West Wing, Ickworth House, Bury St Edmonds, Suffolk♦♦ Saturday 20th October. "All Aboard with Little T". Come along, join in with the nautical theme and have a wonderful time. For full details please contact Tracy: 01284 704656 or [e-mail Tracy](#)



Raising awareness of Vasculitis at the Nuffield Orthopaedic Centre



Violet blowing up a V-UK balloon at Lynne Jacques' tea party.



Green and yellow cupcakes made by [Carla](#) for Lorraine Murton's "Dress in Green and Yellow" day at the [Newmarket Group](#) in Surrey

HealthUnlocked

Join over 400 vasculitis patients on Health Unlocked which is a "private" vasculitis discussion group where you can set your own levels regarding who can see your posts. [join HealthUnlocked](#)



Designer t-shirts !!

Fun "designer" t-shirt from Vasculitis UK. £10 (inc p&p). Sizes S36, M38/40, L40/42, XL42/44



Vasculitis UK bracelet

In addition to our Vasculitis UK

Route Map for Vasculitis

Since the launch of the Route Map for Vasculitis, during Vasculitis Awareness Month, our media campaign, to raise awareness of Vasculitis and of the Route Map, has been proving hugely successful. The biggest boost to raising awareness was an article in the "Nursing Times".

To purchase a copy of the Route Map please contact Susan Mills. These are £10 each including p&p. You can view the Route Map at the Trust's [website](#) A PDF version of the Route Map is available from [Pat](#)



Fundraisers

Why not take time to visit the Trust's JustGiving pages and read the interesting and inspirational stories of some of our fundraisers, like Tim & Francesca (London Marathon), Lorraine, Jimmy (pictured on his recent long and winding 76 mile Scottish walk), Sammi & Marion (walking up Ben Nevis) and Hannah-May?

Many of our fundraisers are like you, they have vasculitis, and they are truly inspirational. Maybe you might be inspired to help their fundraising efforts. Please visit [Justgiving for Vasculitis UK](#)

Contact: John Mills, Chairman
West Bank House
Winster, Matlock, Derbyshire
DE4 1DQ [e-mail John](#)

wristbands (£1.60 each) we now have these beautiful beaded Vasculitis UK bracelets. £4 including p&p.

t-shirts and bracelets available from: Susan Mills, West Bank House, Winster, Derbyshire, DE4 1DQ.



Coming soon

It's nearly summer but don't forget that the Trust will be having good quality charity Christmas cards for sale this year.

There will be four designs to chose from - two traditional and two light-hearted. Above is a taster. More information next time.

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